

Preventing Neural Tube Birth Defects: A National Campaign

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Objectives

After reading this article, the pediatric nurse should be able to:

- Describe how spina bifida and anencephaly are deviations from normal development of the spinal cord.
- State sources and doses of folic acid as preventive measures of neural tube birth defects.
- Discuss the national campaign to reduce neural tube birth defects.

If all women who could become pregnant would consume 400 micrograms (mcg) of folic acid daily, the incidence of neural tube birth defects could be reduced by 50-70 %. (CDC, 1992)

Introduction

[i] Yet, recent Gallup polls sponsored by the March of Dimes have shown consistently that very few women (only 13 percent in 1998) know folic acid reduces the risk for NTDs. Fewer still (only 7 percent in 1998) know that folic acid should be taken before conception.^[ii] The same Gallup polls indicate that less than one-third of the women take folic acid regularly. What a challenge for healthcare providers! Pediatric nurses can help to educate both mothers and teenage girls about the need for folic acid daily.

Did You Know That . .

- Each year in the U. S. about 4,000 pregnancies are affected by spina bifida and anencephaly?
- Spina bifida and anencephaly are the most common preventable birth defects?
- These birth defects occur very early in pregnancy, 3-4 weeks after conception, before most women know that they are pregnant?

- Half of all pregnancies in the U. S. are unplanned?
- Women can be sure to consume 400 micrograms of folic acid every day if they take a multivitamin with folic acid or eat a bowl of cereal with 100% of the DV (Daily Value) of folic acid?

A Review of Spina Bifida and Anencephaly

Between the 17th and 30th day after conception (or 4 to 6 weeks after the first day of a woman's last menstrual period), the neural tube forms and then closes. The neural tube later becomes the baby's spinal cord, spine, brain, and skull. An NTD occurs when the neural tube fails to close properly, leaving the developing brain or spinal cord exposed to the amniotic fluid. The two most common neural tube defects are anencephaly and spina bifida. Anencephaly happens when the upper portion of the neural tube fails to close, and as a result, the brain either is absent entirely or does not develop completely. Anencephaly is always fatal. Pregnancies affected by anencephaly often result in miscarriage, whereas infants with this defect who are born alive die very soon after birth.

Spina bifida takes place when there is an opening in lower portion of the neural tube, which eventually becomes the spine. In approximately 10 percent of spina bifida cases, the defect in the spine results in a meningocele, a sac formed when the meninges protrude through opening in the spinal column and then fills with spinal fluid. In approximately 90 percent of spina bifida cases, a myelomeningocele develops, with the sac containing a portion of the spinal cord and spinal nerves as well as the meninges and fluid. The severity of spina bifida varies with the size of the opening in the spine and the level along the spine at which it occurs. Disabilities associated with spina bifida range from mild, with little or no noticeable effect, to severe, with limited movement and function. Many babies with spina bifida develop hydrocephalus soon after birth and have shunts inserted to reduce pressure on the brain. Although mental retardation is rare among those children because of the early intervention with shunts, many are affected by learning disabilities. Neurologic impairment may also appear as weakness or paralysis of the lower extremities, sensory deficiencies, and impaired bladder and bowel control.^[iii] For most of the affected children, the source of major concern and embarrassment relates to decreased bladder and bowel control. With high-quality medical, physical, and emotional care, most people born with spina bifida will likely have a normal or near normal life expectancy. The Spina Bifida Association of America has available an excellent resource of guidelines for routine health care for people with spina bifida that may be obtained by contacting SBAA, 4590 MacArthur Blvd., NW, Suite 250, Washington, D.C. 20007-4226 (Phone: 800-621-3141).^[iv]

The average lifetime cost for each child born with spina bifida is about \$532,000, but the total cost for a child with severe spina bifida may well exceed \$1,000,000. Repeated hospitalizations may be required to treat associated orthopedic problems, recurrent urinary tract infections, and shunt infections or obstructions. Special equipment, such as braces, crutches, and wheelchairs, may be needed. The equipment must be adjusted or replaced to fit the growing child. The financial expenses of medical, educational, and psychological services for people with spina bifida are great. However, the amount of money spent for those services doesn't address the enormous physical, emotional, and social tolls on the affected individuals, their families, and the community at large.

The Risk for Neural Tube Defects

Any woman who can become pregnant could have a pregnancy affected by a neural tube defect. In the United States, an NTD occurs approximately once in every 1,000 pregnancies.

Currently, it is not possible to predict who might have an NTD-affected pregnancy. Ninety-five percent of women whose pregnancies are affected have no personal or family history of NTDs.

NTDs occur more commonly among whites than blacks and among Hispanics than non-Hispanics. In the United States, the prevalence is higher in the East and lower in the West.^[v]

Folic Acid: An Answer for Many

We don't understand how folic acid reduces the risk of having an infant with an NTD when a woman consumes sufficient amounts before and during the first few months of pregnancy. We

do know that the periconceptional use of 400 mcg of folic acid daily decreases the incidence of NTDs by 50 to 70 percent. Nevertheless, it is important to point out that not all cases of NTDs are prevented by the use of folic acid.

Folic acid is a B vitamin that is necessary for proper cell growth and development. It is required for the production of DNA and protein. It is essential for the rapid cell division needed to make tissues and organs in the embryo and fetus. More research is needed to help us understand how folic acid works.

There are some indications that folic acid use may also reduce the risk for other birth defects such as cleft lip and palate and certain congenital heart defects. Folic acid may also play a role in protecting against some forms of cancer and heart disease. Again, more research is needed to clarify the impact of folic acid in preventing those diseases and other birth defects.

Sources of Folic Acid

Folic acid is a synthetic form of the B vitamin folate. It is found in multivitamins, in a single folic acid pill, and in enriched cereal and grain products that have been fortified with this B vitamin. Fortified cereal and grain products include breakfast cereals, flour, bread, rice, and pasta. Folate is the form of folic acid found naturally in foods. Compared with synthetic folic acid, food folate has a more complex structure that makes it more difficult for the body to process and absorb.

The Food and Drug Administration (FDA) ruled in 1996 that, effective January 1, 1998, all cereal and grain products labeled "enriched" must be fortified with folic acid. There was much debate about the amount of fortification to require. The level of fortification was established at 140 mcg per 100 grams of cereal grain. This level is estimated to add 100 mcg of folic acid to the average daily intake of 200 mcg of folate from other food sources. It was noted that although this level of fortification would help, it would not be high enough to maximize prevention of NTDs. It will take some time to determine the impact of fortification on the prevalence of NTDs.

In April 1998, after a comprehensive review of data, the Institute of Medicine's (IOM) Food and Nutrition Board issued a report recognizing that synthetic folic acid is more easily absorbed than food folate.^[vi] Among the recommendations the committee made was that women capable of becoming pregnant should take 400 mcg of synthetic folic acid daily from fortified foods and/or vitamins in addition to eating a diet that is high in food folate.

An easy way to ensure consuming the proper amount of folic acid is to take a single supplement of 400 mcg of folic acid or to take a multivitamin with 400 mcg of folic acid or to eat a bowl of cereal that has been fortified with 100 percent of the DV (Daily Value) of folic acid in addition to eating a healthy diet with lots of fruits, vegetables, and enriched cereal and grain products.

The National Campaign

Because the March of Dimes Gallup polls conducted in 1995 and 1997 showed only a small increase in knowledge and behavior about taking folic acid, CDC and MOD decided early in 1998 to bring together several professional and service organizations that were involved in women's health issues and preventing birth defects to work on this very important health issue. The organizations represent professional, multicultural, and other special-interest constituents. This coalition was named the National Council on Folic Acid (NCFA). The first organizations that joined in the effort became the steering committee. Many other organizations have enrolled since the council's first meetings.

In 1998, NCFA began organizing a national campaign to educate women of reproductive age about the importance of consuming 400 mcg of folic acid every day to reduce the risk of spina bifida and anencephaly. NCFA has undertaken a 3-year education campaign. Each council partner will coordinate with the members of its organization to participate in the campaign. CDC, MOD, and NCFA held a national conference in January 1999 to provide training for all partner organizations that wanted to help in the campaign. CDC published a resource guide, Preventing Neural Tube Birth Defects: A Prevention Model and Resource Guide, that provides user-friendly technical assistance for conducting local and state folic acid education campaigns to compliment the national campaign. It is available to all who request it. Brochures, posters, public service announcements (PSAs), and other materials are also available.

Health Communications Research for the Prevention Campaign

Extensive health communications research was conducted to identify the intended audiences and to develop the messages and the materials for the campaign. The campaign will target all women of reproductive age, health care providers for that group, and community advocacy groups. Among women of reproductive age, the research results identified two primary target groups for the initial campaign: women who are planning a pregnancy sometime in the near future ("contemplators") and those not planning a pregnancy within the next few years or ever ("non-contemplators"). The researchers integrated what they learned from focus-group participants with results from national surveys. They then developed and tested the messages for use in the community.

Campaign's First Phase Targets "Contemplators"

"Contemplators" generally fall in the 18-35 year-old range and are planning a pregnancy within the next year or so. They would seriously consider behavior change that would improve the outcome of a pregnancy. Fifty-five percent of the contemplators are not currently taking folic acid, but 84 percent would be willing to take folic acid to prevent birth defects. The biggest barrier to overcome with this group of women is the lack of knowledge about folic acid usage. Even those who have heard about folic acid do not know that they need to take it before pregnancy to be effective. Therefore, education about the importance of taking folic acid during this critical period is the objective. The timing of taking folic acid is emphasized in the message to contemplators. The contemplators' campaign began around Mother's Day 1999 with materials calling attention to "Before You Know You're Pregnant."

CDC researchers learned that Hispanic women as a group are more open to becoming pregnant even if they are not actively planning pregnancy. Therefore, Hispanic women are included in the contemplators' strategy. Spanish-language materials are available for this phase of the campaign.

Second Phase of Campaign Targets "Non-Contemplators"

The pregnancy "non-contemplators" are more difficult to reach. Usually 18-24 years old and not planning a pregnancy, these young women are resistant to change a behavior that doesn't "relate" to them. At present, 74 percent of these young women are not consuming folic acid. Pregnancy for them is an event that they will deal with later, if at all. However, the realities are that the average age of pregnancy is 21 and that 50 percent of all pregnancies are unplanned. Reluctant to think about it, the women in this group did admit that they were biologically capable of becoming pregnant ("Ready") even though they were not planning a pregnancy ("Not"). The objective for this group is to raise awareness about taking folic acid now in order to reduce the risk for birth defects someday in the future. The tone for messages to this group is "hip," youthful, and energetic. The message for non-contemplators emphasizes that your body is ready for pregnancy even if you're not planning a pregnancy now. The campaign for non-contemplators began in Fall 1999 with materials stressing that whether you are "Ready . . . Not," you should take folic acid daily.

The materials developed for these two target audiences are available as brochures, posters, and television, radio, and print PSAs. You may obtain those materials from CDC and MOD as well as from other NCFCA organizations.

Join the NTD-Prevention Team

Pediatric nurses are in the unique position of being able to educate and influence all women of reproductive age every day. Women who are just starting their families fall into the contemplators' category. The mothers of the children in your office may be in this group. You should educate those women about taking folic acid daily before conception. Approach non-contemplating teenage girls with the importance of preparing their bodies with daily folic acid for someday when they are ready to think about pregnancy. Mothers who declare that they are finished having babies may still be able to conceive. These women also can be placed in the non-contemplators category. They, too, should be reminded to take folic acid daily, just in case . . .

If your efforts led to the prevention of spina bifida or anencephaly in just one person, all of the time and energy you invested in educating others about the importance of folic would be worthwhile!

References

[i]CDC. Recommendations for the use of folic acid to reduce the number of cases of spina bifida and other neural tube defects. MMWR 1992; 41 (no RR-14): 2-3

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[iii]Hunter AGW(1993): Brain and spinal cord. In Stevenson RE, Hall JG, Goodman RM (eds.): “Human Malformations and Related Anomalies” New York: Oxford University Press, Vol. II, pp 109-114.

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[vi]IOM (Institute of Medicine). Report of the Institute of Medicine Food and Nutrition Board, Standing Committee on the Scientific Evaluation of Dietary Reference Intakes. Washington, DC: National Academy Press, 1998: 8.